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ABSTRACT

This guide was designed to help school support personnel provide direct help to children dealing with death, and indirect help to their teachers. It presents discussion from five seminar sessions on death and dying and their effect on children and on the helping professionals who offer counseling. The preface describes a high school student's reactions to her maternal grandmother's death. The postscript describes the feelings of the student's mother, viewing the same death from a different role. Topics covered in the guide are self awareness, stages of acceptance, grief reactions to death, children's special needs, education development preparation, and managing stress by building school supports. The appendix consists of materials used by the seminars to provide a background for their discussions. (NRB)

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helping children cope with death

a guide for school personnel developed by Sandra Swetland, ACSW and Nancy Calhoun, MSW

ALLEGHENY INTERMEDIATE UNIT

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HELPING CHILDREN COPE WITH DEATH

A Summary of a Series of Workshops on Grief Reactions in Children
Presented by Barbara Shore, Ph.D., ACSW, of the University of Pittsburgh.

This Material is Presented as a Guide for School Social Workers,
Psychologists, Counselors, Teachers and Administrators.

The Workshop and Booklet Have Been Funded by the
Henry C. Frick Educational Commission.

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AUG 4 1980

Background

The Pupil Personnel Program of the Allegheny Intermediate Unit, through its staff of clinical psychologists and social workers, offers (in addition to its direct service to students and personnel) consultative clinical services to school psychologists, counselors, social workers, and home and school visitors who serve the forty-six districts of Allegheny County. In this consultant role, the Pupil Personnel staff has helped to identify various needs of each district's pupil services staff and has thus included in its program offerings to districts, staff support through workshops, seminars and in-service education programs.

Schools are concerned with promoting children's growth and with preventing blocks to their learning which are created by anxiety, fears, etc. School support personnel, i.e., social workers, counselors, psychologists and nurses, deal with problems such as these which children experience and which affect their academic performance. Schools represent the largest single system dealing with the increasing population of children who are experiencing family dissolution through separation, divorce and death. Grief reaction to the loss of a close personal relationship is often acted out in school. Academic performance as well as social behavior is, of course, affected at the time of crisis. If grief work is not completed, the reaction can be an on-going one which can insidiously cripple later academic and social growth.

Although some children receive support from family members in the home at times of loss, many do not. School personnel are usually unsure of how to react to children's loss. Teachers, whose primary goal is academic achievement, deal with numbers of children. Providing children with supportive help in times of loss is even more challenging for them.

School support personnel could, with greater sophistication in the management of children's grief, provide both direct help to these children and indirect help to their teachers. With this goal in mind, the social work staff of the Pupil Personnel division of the Allegheny Intermediate Unit planned a series of on-going seminars for district support personnel in the Allegheny County schools. The program focused upon death, the dying process and their effect on both the helping profession and on the children who they counsel. Funding for the series of seminars and for this publication was provided by the Henry C. Frick Educational Commission.

Dr. Barbara K. Shore, Professor, Department of Social Work, University of Pittsburgh, provided the knowledge base and the sensitive group leadership. Miss Sandra Swetland and Mrs. Nancy Calhoun of the Pupil Personnel staff acted as co-facilitators during the provocative discussions. Dr. Elizabeth Scheide, Director of Pupil Personnel Services helped with the editing of the material. Kathy Juliar, Secretary, Pupil Personnel Services, typed and retyped as this project progressed.

A special thank-you is also extended to Rebecca Calhoun a seventeen year old senior at The Winchester-Thurston School. Rebecca candidly shared her feelings around her maternal grandmother's death. Their relationship was a close one and prior to this she had never experienced the death of someone close to her. Rebecca's grandmother was buried on her seventeenth birthday. The Preface contains her comments around the death of her grandmother. Looking at the same death but from a different generation and role, Nancy Calhoun, Rebecca's mother, shares her feelings in the Postscript.

The Six Chapters in between attempt to highlight both the didactic and the experiential components as well as the discussions covered in the five sessions. The essential concepts are presented in logical progression and are not necessarily in the format in which they were presented during the group. Copies of the material used by the group to provide a background for discussion are also included as an appendix.

Preface

I went to the hospital every day because I wanted to be with her. I was uncomfortable and didn't want to be left alone with her because I didn't know what to say.

On the morning that Grandma died I woke up at 6:00 a.m. and couldn't fall back to sleep until 8:00 a.m. Grandma died in the hospital at 7:50 a.m. I just knew that she would die that morning.

I felt guilty because I couldn't cry or feel sad. I never knew anyone who died. I just accepted it.

I understood about my birthday. Even at the funeral home I accepted her death but didn't fully comprehend. There was nothing I could do so why make myself miserable.

Nothing lasts forever and I have given that a lot of thought. Everything that is really good always ends. I have had a lot of losses before. After one or two losses, you realize that nothing you have is always going to be there.

Our relatives came to see us more than Grandma. People came because socially it is expected. It was good that all of Grandma's sisters were there. "Viewing" helped rather than burying right away. I was there for the viewing and funeral because it was expected of me.

People can only look so long. Then they would sit down and talk. Often the conversation was irrelevant. A lot of people forgot the purpose of why they were there or maybe never knew what the purpose was.

The funeral service was nice. The minister said nice things. There should have been a eulogy given by a friend or relative. Since this wasn't done it was not a complete funeral.

When we went upstairs for the funeral service, I didn't realize that we would never see Grandma again. It was a relief when we left the funeral home after the service. It was such a strain on so many people but not on me. I don't know why. The worst part was while she was in the hospital. It was as though she was somebody else. It was as though she wasn't my Grandmother. I hated to see her lack of independence. Independence is very important. It's important to have control over your own body and not depend on others for everything. It was as though she wasn't there but she was.

It's stupid to cry just because you lose something. You have to accept losses. Grandma didn't cry. It would have been different if she had. The people who were crying were just feeling sorry for themselves. One day at the funeral someone was crying. It was so stupid. I just had to leave.

You have to accept life as it comes and goes. I can easily accept changes. Maybe it was more appropriate for Grandma's sisters to cry. When they did cry it was brief. There are other ways to mourn besides crying. I admire Grandma for her strength. I saw some of myself in her. We had our differences but I knew that we could always resolve them. We both liked to have our own way. I liked having my best friend at the funeral. She also respected Grandma.

There is a degree of change but actually things will go on. The loss isn't so much what she did for us but the loss is her presence. Everyone she came in contact with had some kind of loss. Society puts too much emphasis on losing people and material things but if you can still depend on yourself to live, make yourself happy, keep busy with meaningful things . . ., Grandpa falls into that category. He depends on himself. It is a big loss to him but everyone is making it bigger than it really is. That way it carries over to him and that's too bad. I accepted it much better because I'm only the Granddaughter. People laid the load of the loss on you and Grandpa. People felt sorry for the two of you over the loss. Their attitudes and what they said encourage self-pity.

Society handles death wrong. I know you won't agree but you should have told Grandma that she was dying. It was her right. That was a violation of her rights. I would have wanted to know. You denied her those last few days to see things as a dying person. Dying people see things differently. Who are you to decide that was for her own good. I know that I wouldn't want to be the one to tell her but I would want someone to tell me. I know no one would want to tell me. I think she was left out of her own death. Everyone else knew about it. I think that was wrong.

If people were going to come to the funeral I would want them to remember why they were there and not talk about baseball. I wouldn't care how long they stayed if they remembered the purpose. The worst thing was that most people didn't know or understand the purpose of being there. When they started to talk about anything unrelated to Grandma I left. It wasn't a place to laugh. Everyone could use a few lessons on funeral etiquette. I remember from school that visiting is for the family and not for the dead person. We had Death and Dying at school for a week and that helped.

It's worse to suffer emotionally than physically. Grandma had a secure life and was a secure person. Her suffering was physical. That's why I don't feel as badly about it.

Rather than just seeing death as a loss it also means assuming more responsibility. You begin to do some of the things they did for you that maybe you didn't like to do yourself. (Smile) Now, I clean up after myself.

Chapter I

SELF-AWARENESS

The series began with a discussion of death and it's treatment of society at large. Utilizing responses of the group to the question, *"Why are you a participant in this seminar program?"* Dr. Shore developed the major theme of self-awareness. *"One cannot really be comfortable around others who have experienced loss unless one has explored his own feelings about death. Anything that happens to us here in this seminar is part of that ever-growing, ever-developing exploration."*

She then moved to the reasons for difficulty in dealing with death and dying, particularly for 'helping' people. *"One of the reasons for this is that whenever we confront death, either in ourselves or with other people, it touches within us our own sense of life and death. If we can actually explore where we are and how we have faced this sense, we can appreciate the feeling of youngsters and families who are facing death."*

One of the most pervasive and universal of those feelings is death anxiety. We all experience it. Most people deal with anxiety through denial and withdrawal, especially when, as is often the case, there is a feeling of anger underlying the anxiety. Research has shown that some cultures deal with death more comfortably than do others. Ours is one of those which does not deal at all comfortably with death. Denial and withdrawal from death has, thus, become a cultural pattern.

Anger surfaces when we look at death, both that which we have experienced and that which we anticipate in the future, including our own. When someone dies, we experience not only the loss of the deceased, but the feeling that we have lost some sort of battle with death. Anger, then is in response both to the feeling of losing the battle as well as to the tremendous emptiness caused by the personal loss experienced. Anger toward the deceased is unacceptable, therefore, the anger is displaced. Consequent arguments may arise among relatives; funeral arrangements may be criticized; even the conventional religious burial rites may become the focus of anger. Among younger people, these rites are sometimes seen as distancing or as hypocritical; at the same time, these conventional rites may be very comforting to older members of the family and may be of help in their coping with their loss.

We live in a scientific and technological society which has led us to believe anything is possible: where mechanical devices and medical science have prolonged life to such an extent that a dying person is seen as having lost in confrontation with death. Losing is uncomfortable, both for the medical community as well as for the family. This discomfort is often felt as helplessness leading to denial of the imminence of death and even more important to denial that the patient, himself, knows that he is dying. Often the dying are avoided as death approaches. Breaking through the denial to permit acknowledgement of the anger which accompanies death and exploration of the felt loss are beginning steps in uncovering the source of death anxiety.

During the seminar, shared group experiences about death helped group members get in touch with their anger and their sense of loss. Other themes also emerged. The cultural pattern of denial surrounding death was one of these as delineated by one participant's recall: *"My Grandmother died when I was nine years old. She lived in the same house with my family. My parents prepared me by telling me that she was close to death. However, before she died, an uncle took all the children away until after she was dead and buried. Children were not to be at funerals. Later, when my father died, my children were very much a part of things and they shared with me the feelings and experience with death."* Another participant's recall demonstrated the isolating experience she had: *"When my Father died, I remember coming home for lunch. My Mother was crying in the kitchen. Later some Aunts came. There were a lot of people in the house. I had to get my own lunch."* In some families death is still a forbidden topic, almost obscene. Feelings about it are not to be discussed. This can lead to a sense of exclusion and confusion about feelings especially in young children who are often excluded from the experiences at the funeral home, the memorial service, etc.

Fears about death are, of course, natural. But these fears are enhanced by the factors discussed above. Some common fears about death and dying are:

Fear of Causation. There may be *"magical thinking"* leading to the belief that the one or ones who remain alive caused the death in some *"magical"* way. This magical thinking is especially found in younger children who may have wished a parent dead in a moment of rage. Guilt feelings nay well exist concomitantly with magical thinking.

Fear of Abandonment. Many fear being left alone with no one left to help.

Fear that death is *"Communicable."* Some people fear they can *"catch"* the disease or be influenced by whatever caused the person to die and will thus avoid people and things which have been in close contact with the deceased person. This is especially true of young children, who will often back away from those who have experienced death in the recent past.

Fear of Pain. No matter how well we help someone go through the process of dying, there is no way to avoid the pain that may accompany the death. Even when the primary pain is *"treated,"* many people who are dying have other pains and discomforts which go unattended by the caretakers who are focused on the pain of death and on the death itself.

Fear of giving up the familiar for the unfamiliar. This fear is even stronger than the fear of the unknown. Often, our fantasies about what a situation might entail is what *"does us in;"* the fantasized fear is usually more distressing than the reality. The power and impact of such fantasy is lessened through understanding what is actually experienced in the reality.

Chapter II

STAGES OF ACCEPTANCE

The acceptance of the reality of one's own death can be divided into five separate stages. People generally do not move through these stages in any given order but move back and forth through them.

Denial and Isolation. This stage is marked by resistance to the new reality. *"This cannot happen to me. I am not ready to die."* The resulting feelings of isolation can be made more intense by one's hospital experience. During hospitalization, control over one's body and life experience are usually taken away; one is separated from one's family so that, although family experiences continue, the patient is not an active part of his family life.

Bargaining. This stage often serves a sustaining purpose. Bargaining helps to gain control and thus to remove a sense of powerlessness and vulnerableness. One might *"strike a bargain"* with the Divine Power *"to be allowed to continue life at least until a certain time or event in life has been reached."* Knowing the end is near tends to make the person *"recast"* his life. One becomes more concerned with the *"here and now"* and less concerned about the future.

Anger. Much anger gets felt in such questions as *"Why did this happen to me? What did I do to deserve this?"* Anger often gets *"dumped"* onto irrelevant situations; for example, it becomes directed toward food in the form of not having an appetite or of being very critical of the food offered. When family and hospital don't understand the source of the anger, it escalates and creates larger problems.

Guilt. Guilt often accompanies anger. Guilt may manifest itself over unfinished business or over things perceived as done wrongly, that is, over omissions and commissions.

Acceptance. Few people reach this stage. People who are able to let go are those who feel they have accomplished their life tasks. There is comfort in completing unfinished business such as expressing true feelings to others, expressing tenderness and anger, saying *"good-bye's"* before dying.

People do not generally move through these stages in the order in which they are listed above but move through denial to bargaining, back through denial to bargaining, etc. Those most likely to reach the stage of acceptance are those who accept themselves for who and what they are and who are satisfied with their lives' accomplishments. It is for these reasons that those in their youth and middle age are less likely to reach the acceptance stage.

Chapter III

GRIEF REACTIONS TO DEATH

When the death of a loved one occurs, certain responses are common and emotional reactions to loss follow a predictable course. Although these responses are difficult to deal with, knowing what to expect may be comforting to the person directly involved as well as to those who attempt to help him deal with his grief. Again, it is useful to look at grief reactions as a process with stages.

Stage One begins immediately after death and may last up to a week.

Acute Grief

- Feelings of shock, disbelief, denial and numbness.
- Quickly alternating emotions, weeping, crying alternating with laughter for relief.
- Irritation with family and friends who are usually trying to be helpful.
- Sensations of physical distress, feelings of tightness in throat, choking, shortness of breath. A tendency to avoid these feelings and "get through" the funeral rites creates a sense unreality and numbness for some. Others experience intense outward grieving and weep and cry easily. The role of the grieving person may determine his behavior during this period. For example: the wife of a deceased may give vent to emotional displays and be "allowed" to grieve openly. A son, on the other hand, may feel he needs to "hold himself together" and busy himself with arrangements.

Stage Two peaks between two to four weeks after death and begins to subside after five months, but lasts in some degree about a year.

Grief Reactions

- Senses are often slightly altered. A feeling of emotional distance from others is common.
- A grieving person may seem preoccupied and restless but at the same time lost interest in usual pursuits. Insomnia and loss of appetite are common.
- There is often a disconcerting loss of warmth in relationship to other people, a tendency to respond with irritability and anger at a time when friends are making extra efforts to maintain relationships.
- Feelings of sadness, tearfulness and longing may come and go in waves. There may be an intense preoccupation with mental images of the deceased. Feelings of guilt emerge easily. The bereaved mentally searches the time before death for evidence of failure to "do right" by the deceased. He accuses himself of negligence and exaggerated minor omissions.
- Changes in physical activity often follow a death. The bereaved person is surprised to find how much his usual activity was related to the deceased and now has lost its significance.
- A sense of the deceased being present is common as well as the appearance or traits of the deceased in the bereaved.

Stage Three should begin to occur about a year after a death.

Grief Work

- The accute grieving process and subsequent long-term mourning process are ultimately resolved as the

person detaches from the memory of the deceased and accepts the reality of the loss. This results in decreasing episodes of sadness, and ability to recall the past with pleasure and resumption of normal activities.

- The duration of a grief reaction seems to depend on the success to which a person can adjust to the environment without the deceased, and eventually form new relationships.

- This process can be complicated by various factors. One is the relationship of the bereaved to the deceased. Most relationships are complex and contain both positive and negative elements. In a relationship which was perceived as difficult and problematic, many people try to avoid the intense distress connected with the loss and avoid expression of emotion connected with it. Ambivalent feelings may never be resolved or grief work may take place over years and complicate future relationships.

- Another factor which effects interpersonal relationships is that each family member may move through the process at his or her own pace, may flow back and forth between stages and may be in a different stage at a different time.

Chapter IV

CHILDREN'S SPECIAL NEEDS

When dealing with children, the questions and feelings about death must be re-examined and resolved at each developmental stage. The younger the child, the more vulnerable to loss and fantasy. In general, the following thought processes occur in children:

Under five, death is seen as totally reversible. Since anxiety separation occurs each time a pre-schooler is away from the primary "caring"parent, this anxiety may initially be similar. Memory fades more quickly, but sleep disturbances may occur.

From ages five to nine, death is viewed as remote if not reversible; death becomes personfied as "ghosts," illogical thinking is probable.

After about age ten, a child becomes aware of reality and finality of death. The older the child, the more cognitive information may help in understanding the process.

However, adolescence is generally a time of stress and anxiety in itself and a death experience at this time may create more anxiety.

Dealing with feelings of anxiety and guilt and moving toward resolution can bring a family together or create barriers between family members. Children can be helped to deal with loss in a healthy way by sharing it in the following ways:

- Acknowledge observable reality. Don't deny the obvious to a child.
- Share the truth and more importantly share your feelings about the truth. State how you feel about what has happened and encourage the child to do the same.
- Strive to include children in all rites and ceremonies that custom and tradition call for, but try not to force participation. At a time when crisis creates emotional turmoil, each person needs the protection of a feeling of belonging.
- Encourage mastery of the experience through asking questions, talking.

After a Death Occurs

Huge amounts of energy get tied up in the caring process and when death occurs, we have to reorganize lives. Children may sense a feeling of abandonment. In the first days or weeks following death, a child may seem to be in a denial stage, although may really be unbearable pain or shock. A child then may display anger, again often related to guilt. Acting out behavior will be seen in youngsters. Encouraging discussion is important to dealing with feelings. Also, normalizing child's life is crucial. One way is through school activities. Getting back into school as soon as possible and experiencing peer support.

Provide opportunities for mastering feelings of vulnerability and powerlessness - *What are the things I can control?*

Be aware of the child's expression of feeling through play, drawing and behavior. Changes in behavior indicate anxiety. Although it may seem difficult, the anxious child can be helped to understand sometimes there is no " justice" or fairness in death. No matter what the circumstance, it can be dealt with after it is accepted.

Chapter V

EDUCATIONAL DEVELOPMENT PREPARATION

In its simpliest terms, death is a fact of life. As such, dealing with death can be seen to be eased somewhat with the use of events which may prepare a child for the death of one close to him or her.

Preventive mental health has borrowed the concept of **Immunization** from medicine to describe a way of preparing people to cope with life crises. In physical immunization, a small dose of a disease agent will help the body resist exposure to the disease. Exposure to small experiences which foreshadow large life crises will help a person practice for and be more prepared for these crises.

Limited Experience

Exposure to low anxiety versions of a stressful situation can have an immunizing effect. Discussing feelings about death of the class hamster or change of class plans can give students experience with handling some of the losses and changes which are an inevitable part of life.

Children get "practice" in coping by experiencing the loss by death of animals and pets. However, the adults in the situation must use it by dealing with it honestly and realistically. This also allows for the feelings of the child.

It is important to avoid immediate replacement. If a pet dies, immediately replacing with another pet without the grieving process taking place is a very hazardous thing to do. (If I die, nobody will remember me; they will replace me right away.)

Reflection

When a death occurs which does not "touch" a child directly, attempt to respond to the questions the child asks. Offer as much information to the child as needed. Extremely important not to use the analogy that death is sleep. Answer questions at the level they are asked. The more children are prepared before a close person in the family dies, the less frightening death experience will be.

When people can talk about previous experiences with death, loss, illness, accident and other life crises, children can learn from looking back at their experiences. Encourage remembrance of a dead person at appropriate times.

It is important to be open with children and to not have "family secrets" or taboo topics that are never talked about in the family circle. The more one is involved in the family circle and its dealings, the less a feeling of abandonment or exclusion at the time of a crisis. The more death had been dealt with naturally as a subject in a family circle, the less traumatic dealing with the reality of death when it occurs.

Expect irrational behavior. Some children will cry and overreact to small stresses; others may clam up. They may blame those who aren't at fault and resent people they ought to be grateful to.

Reminisce. Don't brush memories aside because they might be painful. Remember the good and the bad in detail. Reminiscing honestly about the past is the first step toward a healthy future.

Help the child learn that it is possible to experience a whole range of uncomfortable feelings and to survive and to find ways to cope.

Chapter VI

MANAGING THE STRESS: BUILDING SCHOOL SUPPORTS

Children have difficulty showing sadness. Adults may interpret their denial and anger as *"hardness."* Youngsters need to see adults who model helping and understanding behaviors. In order to deal with children's anxieties, adults must learn to deal with their own anxieties and fears about death. Only then can they deal with children in a more open manner so that the child's experience is less crippling and ultimately less damaging to his healthy adjustment.

In school settings, all staff can begin by providing support for one another's sadness and grief. Dealing openly with the pain helps to heal it. Throughout the school year, some building personnel are usually experiencing some loss, separation or death. Being aware of each other's needs creates an atmosphere where teachers become more sensitive to what is happening to children through their behaviors, verbal expressions (or lack of them) and drawings. Becoming sensitive to behavior, a teacher may detect early symptoms of distress and decide whether a child needs to be referred to a school counselor or to an outside mental health resource. More often than not, children are referred for counseling only if their behavior becomes very deviant.

The helping person, counselor or teacher, can intervene directly with the grieving child in several ways, but must first recognize and respect the child's current stage of grief. Through reality testing, the child's distortions can be corrected. Here, the helping person will ensure that the child knows what is and what is not happening. The child's ability to cope can be supported through a mutual recognition and recall with the child of other challenges and losses with which he has coped successfully in the past. Although children should not be asked to assume roles beyond their present developmental level, neither should their regression be encouraged. Expressions of grief and sadness should be heard, should be supported and should not be confused with regressive behaviors. In the hands of a school counselor, social worker or psychologist, play therapy can be used as an excellent tool for allowing the child to act out his feelings.

Counselors and teachers can also be helpful to the child's parents and other family members who may be too closely identified with the loss to be of immediate help for the child. Counselors can help parents to assess what is useful for the child. The parent's sensitivity to questions which may lie behind children's behavior can be enhanced by the counselor. The parent can be helped to "tune-in" to depth which may lie beneath a superficial question asked by the child. Parents can be taught active listening skills through the use of open-ended questions to the child such as, *"What makes you say that?"* or *"What do YOU think?"* or *"Tell me more about that."*

Sorrow then, cannot be denied. Life goes on and the expression of that sorrow supports healing. The school setting offers on-going opportunities for preparing students for dealing with the ultimate life crisis. Putting thoughts and feelings into words is the most useful vehicle for helping students learn to master the difficult experiences of life.

Postscript

WORKING IT THROUGH

During the course and completion of this series of seminars, the Mother of one of the co-facilitators died. We were thus in an ideal position to put into effect our new learning about the process of working through the death of a loved one. The thoughts of our co-facilitator were recorded by her at the time of her Mother's death:

"Sudden, Unexpected, Denial, Disbelief, Fighting the battle against death to prevent the inevitable. These are the words that come to my mind when I think of the death of my Mother. Self-awareness about death and knowing the stages the family goes through were of primary importance in coping with what was happening. It didn't change the feelings but I was better able to deal with them on a more conscious level.

There was a lot of displaced anger that had to be dealt with. Usually this centered around the 'inadequacies' of doctors. Then there was mobilization but in a helpless way. Knowing the battle against death would be lost but continuing to hope. Always coming full circle to the realization that there was no hope.

Guilt. Reviewing what had been done and trying to think what could have been done differently. Needing to do this within my own thoughts but also with my Father, our doctor and the nurses. Always coming back to the helplessness that there was nothing else to do. Knowing that what I wanted was magic and no one had that to give. The helpless feeling of not being able to provide my Mother, a person who had given so much to me, with what I deemed important - life.

Trust. The loss of trust was focused on the doctors. We flowed in and out of that. Usually reminding ourselves that no doctor wants his patient to die. However, the life of the patient was in their hands and they couldn't come up with the magic we so badly wanted. Communication with the doctors was less satisfying than communication with the nurses. Part of this was the fact that the doctors were less accessible than the nurses. I also found the nurses more willing and comfortable about answering my questions directly and clearly. Oftentimes, the changing condition of the patient made what the doctor had said the day before invalid. Because of our anger around the loss, hearing was difficult. The doctors were also the ones to give us the bad news which proved to be worse each day. It was like being hit over the head everyday of the illness, staggering with no one to reach out and steady you, integrating the information and then weakly mobilizing to do the little you could for the patient.

The nurses are seen quite differently than the doctors. They were our allies in the battle against death. Not only were they more accessible but they could be seen taking care of the patient. That made quite a difference. They were always there when we needed them.

The nurses considered not only the patient but the family as well. The last time they made my Mother's bed they made sure she had floral sheets. Although she was too ill to notice, we did. When I commented that I had never seen my Mother's fingernails dirty before, the nurses made a point of cleaning them. I needed to know what stage of the dying process my Mother was in since I was more comfortable handling the situation on an intellectual basis rather than purely emotional. The nurses kept me informed and in that way cushioned the impact of the death when it came. It was comforting to get the telephone call telling me my Mother had died from a nurse that had been involved and so helpful. She was able to answer my few questions openly and clearly. She also knew that I would be concerned about my Father who had stayed with my Mother. The nurse was able to give me her perceptions of how he was handling my Mother's death. I knew I could trust her and in this way was better prepared when I arrived at the hospital.

The only one of the doctors who would answer my questions about how much longer my Mother had to live was our family doctor. He pin-pointed it with three or four days. I know no one could say exactly when but I felt that from past experience and the rapid daily deterioration the doctors could give me some idea. I wanted to do as much as I could and be with my Mother. Knowing there was so little time, I was able to abandon other responsibilities and focus on what was the most important.

My Father and I felt that there was no unfinished business as far as my Mother was concerned. We talked about it and decided that there was nothing we would have done differently in our time together. That was comforting and gave us some strength to deal with our feelings around the death. Two days before she died and I knew she could still understand, I needed to say, 'You know, Mother, that I love you very much.' The unspoken family rule had been that love was shown by how one treated a family member. Rarely was this said verbally. She was very weak and barely able to say even one word. However, she said, 'Yes.' I needed to hear that from her and as soon as that was said by both of us, I knew there was nothing else to say. I was alone with her then. When my Father arrived, I told him that the restlessness we were observing meant that possibly she would be going into a coma soon. Thanks to the nurses, I was prepared for that. I told him that I had said what I needed to say to my Mother and suggested that he do the same. He nodded his head and I left them alone.

After we were told that the illness was terminal, my Father and I decided that one of us would be with my Mother at all times during the day and evening. We felt that since she had always been so particular about her appearance she wouldn't want anyone to see her now. Her stomach was huge from the wild and rapidly growing tumor. It was almost as though we were isolating and protecting her from outside forces that even we didn't understand. As her condition rapidly deteriorated, we suddenly realized that she now had other priorities. She wanted to see her sisters. On the third and second day before she died, we permitted them to come into her room for a short period of time. By now her eyes were closed most of the time and it was difficult for her to speak even a word. However, we knew that she was aware of their presence and it was important to her. They also had a need to be there. The only other person who had freedom to enter the hospital room was my daughter - my Mother's only grandchild. She always asked for her. I found myself on the second day before my Mother died telling her about the cards that had arrived and the people who cared about her. I needed to let her know how much everyone cared and surround her with these thoughts.

My Father and I had agreed there would be no crying in my Mother's room. We grieved a lot together and provided each other with support. Our crying was sporadic and silent but never in the room. I remember being in the hospital corridor when one of my friends arrived. She reached out to hug me and at the same time asked how I was. I was surprised to hear myself sobbing deeply for the first time and really letting some pent-up feelings surface. My Father and I received a lot of support from family and friends. They came to the hospital and spent short periods of time with us although they weren't permitted in the hospital room. This was helpful to us while we participated - so ineffectively - in my Mother's battle with death.

During the last three days, my Father stayed during the night. My Mother died early Monday morning. I spent the night with my Mother and Father on Saturday. During that day my Mother said my name and my Father's frequently. By Sunday, she was only saying my Father's. Earlier I had planned to stay Sunday night as well. It become apparent to me that my Mother was looking more and more to just my Father for support. Their marriage had been a happy one and they were very close. We had all been very close but by Sunday evening I felt that perhaps they needed to be alone - just the two of them. When my Father suggested that I go home for a good night's sleep, I agreed. My Father was with my Mother when she died and I felt that was as it should be. I was called to the hospital early Monday morning. My Father met me outside of the hospital room and told me what had occurred during her last moments. I wanted to know. We went into her room together. He was concerned about the way she looked and had suggested that perhaps it would be easier for me if I didn't see her. Death had taken its toll but she was my Mother and I needed a few more minutes with her. Her appearance had mattered so much to her so I combed her hair briefly before she was taken away. I needed to do one last thing that I knew would have been important to her.

The nurses again were so helpful. My Father left while I gathered up the last of my Mother's things. The nurses then suggested that I go to the nurses' room and have a cup of coffee. The nurse who had called me came in to talk to me. Since I had been dealing with a lot of this on an intellectual basis, there were still some things I needed to know that my Father wouldn't be able to tell me. The nurse anticipated this and filled me in on such things as when my Mother went into a coma and how long after that she died. Our family doctor came in to talk to me. I felt dazed. Everything had happened so suddenly. Did it really happen? Yes, it had, For the first time, I had seen death and realized what a difficult process it is for the person going through it. Only a small part of it can be shared with others. It is something that each of us must endure basically alone. No one can really help or turn it around. 'For everything there is a season' and that kept going through my mind."

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